

CHAPTER 1

INTRODUCTION TO HOSPICE

*While Hospice is care for the dying,
it places special emphasis on life and on living each day
as fully as possible, with the hope of making
the very best of today.*

—Larry Beresford,
Hospice Handbook

CHAPTER 1

INTRODUCTION TO HOSPICE

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CHAPTER 1

INTRODUCTION TO HOSPICE

This chapter provides an overview of the history, basic ideology, and guiding principles of Hospice. Many of these principles are explored in further detail in subsequent chapters.

A Vision for Better Care at the End of Life

Death and dying are not easy to deal with. Perhaps you or someone you love is facing an illness that cannot be cured. Few of us are really ready for the hard choices that may have to be made at the end of life. It can be hard for everyone involved—the dying person, their family and loved ones, and health care providers too. But there is a way to ease pain and make life better for people who are dying and for their loved ones. It is called palliative care.

Palliative care means taking care of the whole person—body, mind, spirit—heart and soul. It looks at dying as something natural and personal. The goal of palliative care is that you have the best quality of life you can have during this time.

Some health care providers—doctors, nurses, social workers, pharmacists, clergy and others—have learned how to give this special kind of care. But all health care providers should know how to give good palliative care or to help you find someone who can.

— *From A Means To a Better End: A Report on Dying in America Today, 2002,*
available at www.lastacts.org.

I. HISTORY AND PHILOSOPHY OF HOSPICE

A. Definition of Hospice

Originally, the term "hospice" was a medieval name for a way station where pilgrims and travelers could be replenished, refreshed, and receive care. **The word "hospice" comes from the Latin word "hospes": meaning to host a guest or stranger.**

Hospice (has'pis) n., Fr., hospitium, hospitality, inn, lodging. A house of rest and entertainment for pilgrims, travelers or strangers for the destitute or sick. (English Oxford Dictionary)

. . . For the ayde and comferte of the poore, sykke, blynde, aged and impotent persones . . . whereyn they may be lodged, cheryshed and refreshed.

(-from a petition by the citizens of London to Henry VIII, 1538)

Hospice is not limited in its definition by describing a particular place, but rather, hospice is an ideal and philosophy of care for a patient with a life-limiting illness and for their loved ones. The purpose remains the same — hospice exists to provide support and care for people in the last phases of an incurable or life-threatening disease so that they might live as fully and comfortably as possible.

B. Early History of Hospice

In Europe with the spread of Christianity, monasteries started to take in the sick and those disabled and unable to support themselves. Then wealthy women and widows in the sixth and seventh centuries started working in these monasteries as the first “nurses.” From the time of the Crusades, from 1095 to the end of the seventeenth century, weary travelers found places of refuge in monasteries and nunneries. Often they were in ill health and many spent their last days cared for by the monks, nuns and charitable working women.

As medicine and hospitals developed, ill people were treated in hospitals, but disease would often spread there and people would die from acquired infections. Families often preferred to keep their loved ones at home, fearing that they would not leave "the house of death" as the hospitals were sometimes called. Neighbors would help support the family with food and clothing.

After WWII, hospitals gained a better reputation as medicine and practices improved and more lives were saved. Subsequently, those who died were seen as the failures of the medical system since all efforts were directed to save lives.

The name “hospice” was first applied to the care of dying patients by **Madame Jeanne Garnier who founded the Dames de Calaire in Lyon, France, in 1842.**

The name was next introduced by Mary Aikenhead whose order of nuns, the Irish Sisters of Charity, opened the first modern hospice in Century Dublin. One of their main tasks was to offer care for the dying. Earlier, Mary established a special kind of nursing home just for these dying patients. She wanted it smaller and quieter than an acute care hospital, but with similar bedside nursing facilities available. In order to meet this more intimate need, she decided to use her own home in Dublin, using the old name of “hospice.” It reflected her assumption that death is the beginning of a journey rather than an end, and the name “hospice” was appropriate in referencing the custom of pilgrims on their journey to the Holy Land.

Mary Aikenhead worked tirelessly to organize the sisters and supervise their charitable works, as their mission spread from one community to another. During the plague of 1932 these nuns were sent on missions as far as France and Australia to aid the sick. Even as Mary’s own health declined, she continued to organize and inspire the work done by the Irish Sisters of Charity from her bed during the final years of her life. Mary Aikenhead died at the age of 71. In 1858, the Irish Sisters of Charity continued her work and opened **Our Lady's Hospice, Harold's Cross, in Dublin on December 9, 1879.** Newspaper reports at the time hailed the opening of the hospice as “a unique charity” and as one “previously unknown in these islands.”

In the United States, Nathaniel Hawthorne's daughter, Rose, cared for her friend Emma Lazarus (the poet whose words are inscribed on the base of the Statue of Liberty) as she suffered with cancer and died in 1899. Rose Hawthorne Lathrop began to wonder how the poor fared when similarly afflicted. After her husband's death, Rose became a nun and founded an order of Dominican nuns who devoted themselves to terminal care. They opened their first hospice in Lower Manhattan and then another in New York, followed by others in Philadelphia, Atlanta, St. Paul and Cleveland.

Although unknown to each other, Jeanne Garnier, Mary Aikenhead and Rose Hawthorne Lathrop shared a common purpose in their concern for the care of the dying, and in particular the dying poor. Directly and indirectly, they founded institutions which, in time, led to the development of homes and hospices elsewhere. They also established a precedent for what was to follow, setting some of the groundwork for modern hospice and palliative care work.

These early hospice institutions placed a strong emphasis on the cure of the soul, even when the life of the body was diminishing. Through charitable endeavors, they gave comfort to the poor and disadvantaged. They were not, however, places in which the medical or nursing care of the dying was of any real sophistication. Rooted in religious and philanthropic concerns, the early homes for the dying represent the prologue to a period of subsequent development, which got underway in the decades after World War II.

C. Development of Hospice

In London in 1967, Dame Cicely Saunders opened the first true modern hospice, St. Christopher's. Saunders was inspired by a patient, David Tasma, whom she met in 1948 when he was hospitalized with an inoperable cancer and she, a former nurse, was working as a medical social worker. The two had discussed how she might one day open a place that was better suited to pain control and preparing for death than a busy hospital ward. When he died, Tasma bequeathed £500 and told Saunders, "I will be a window in your home."

Already a nurse, Cicely gave up social work and studied medicine. She became the first full-time Medical Officer at St. Joseph's Hospital, a house in London made possible by Mary's Sisters, and put into action her conviction that pain for the dying is unnecessary.

St. Christopher's hospice was founded on the principles of combining teaching, clinical research, and expert pain and symptom relief with holistic care to meet the physical, social, psychological and spiritual needs of its patients and those of their family and friends. It was a place where patients could garden, write, talk — and get their hair done. This opening followed years of work researching pain control and developing plans for this special kind of home — where the staff helps a family to "make this part of their lives into real living, not merely existing."

The concept of St. Christopher's was to combine modern medical techniques with individual spiritual commitments, creating a safe haven for the dying. At St. Christopher's, all the threads of experience from Europe and the United States were woven together for the first time, creating a system of comprehensive care and providing a "legitimate end to a natural process."

Through many visits and lectures made in the United States by Dr. Saunders, the hospice atmosphere that she established in London began to catch on in the States. The modern techniques of hospice, such as pain relief, medical symptom management, and grief support for the terminally ill and their families, began to be instituted with the new pioneers of the hospice movement. Saunder's ideals have spread around the world, giving her the reputation of being the founder of the modern hospice movement.

“You matter because you are you. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also to live until you die.”

— **Dr. Cicely Saunders, the founder of palliative care**

Another important development in hospice work was the appearance of *On Death and Dying* by Dr. Elisabeth Kübler-Ross in 1969. The book became a best seller, bringing the topic of end of life issues into public awareness and conversations. Based on more than 500 interviews with dying patients, Kübler-Ross wrote about the common stages she witnessed most people experience as they dealt with their grief. She argued that home care was preferable for the terminally ill over institutional care and she championed the idea that patients should be able to participate in decisions regarding their treatment. Kübler-Ross opened the door for hundreds of professionals in medicine, psychology and spiritual practices to continue her research on death and dying.

Furthering the progress of modern-day hospice services, during the 1970's, Dr. Sylvia Lack pioneered "Hospice, Inc." in New Haven, Connecticut. The first hospice home care program in the United States was Connecticut Hospice (funded by the National Cancer Institute), which began in 1974. In 1978, Dr. Lack began work on hospice homes, which opened the following year.

In 1982, November became National Hospice Month.

In 1983, the Medicare Hospice Benefit passed both houses of Congress, and was signed into law, providing Medicare-eligible terminally ill patients with an option of hospice benefits.

Currently, there are over 200 hospice programs in California and over 5,200 programs across the country. Hospice agencies are estimated to have served more than 1.5 million patients in 2011.

D. Philosophy of Hospice

Hospice is not a place, but a philosophy of care.

Hospice recognizes dying as a normal process, whether or not it results from disease. Hospice neither hastens nor postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring, sensitive community, clients and their families may be free to attain some degree of mental and spiritual preparation for death that is comfortable to them.

Hospice affirms quality of life by providing support and care for persons experiencing debilitating illness and/or grief so that they may live as fully as possible. Hospice SLO is

dedicated to supporting the dignity of the human experience. It is designed to help patients live at home, stay as active as possible, and express and accept their feelings.

Hospice SLO incorporates the principles of the integration of mind and body to support people in living to their full potential. This is true for those who have no apparent health challenges, as well as for those with life-threatening illnesses. Our hospice promotes quality of life at every stage of the life span.

By utilizing a holistic approach, we consider all aspects of our clients and their families as valid areas of therapeutic concern. We understand the experience of dying is unique for each person and that the goal of hospice care is to be sensitive and responsive to the special requirements of each individual and family.

E. Hospice SLO

Hospice SLO began in 1976 when a group of local citizens met to discuss the problems and needs of the terminally ill in our county. In October of 1977, Hospice SLO was incorporated as a non-profit, community-based, and volunteer organization with a fourteen-member Board of Directors. Office space was originally donated by the Unity Church of SLO. Community education and outreach began during this time and direct In-Home services followed in August 1979.

In February 1979, Hospice SLO hired its first employees, an administrative director, program director, and secretary. Hospice SLO services were designed to function in cooperation with the home health agencies of the county, not to provide medical direction and intervention.

In May 1980, the Board of Directors made a policy change to develop a program that would meet the National Hospice Organization standards of care. A nursing coordinator and counselor were hired at this time, and a volunteer medical director was added to the staff in order to coordinate nursing and social services. Hospice support groups were also formed.

In December 1981, Hospice opened the doors to its new office at 559 Marsh Street, San Luis Obispo, and continued to provide “grass-roots” volunteer hospice care in the community. Hospice SLO has always offered services free of charge and are financially supported by local communities.

By the late 1980s, the hospice movement saw a dramatic shift to Medicare-certified programs. Although the Medicare benefit has had a powerful effect on providing credibility and financial security to the hospice movement, it also has produced a significant challenge to the hospice field. At issue, in particular, is the effect of Medicare regulations on the original hospice philosophy and the barriers that regulations present for access to hospice care, often to those most in need.

Volunteer hospices are dedicated to providing access to all who are coping with a life-threatening illness in the community regardless of whether a condition or situation meets specific requirements. In fact, volunteer hospices can elect to serve those who still choose to pursue curative treatments, such as chemotherapy, radiation, or surgery, if that is their choice. Although most volunteer hospices do not provide skilled medical care, they offer a

comprehensive array of services which would be difficult, if not impossible, to achieve in a setting restricted by third-party reimbursements or regulatory mechanisms.

In 1989, Hospice SLO and the Home Health Agency of San Luis Obispo County entered into an agreement whereby Hospice provided free volunteer and bereavement services so that the County Home Health Hospice Program could offer the Hospice Medicare Benefit. This partnership continued in place until the summer of 1999, when more stringent Medicare regulations necessitated a change in the hospice model in San Luis Obispo County.

There are three medically certified hospice agencies serving San Luis Obispo County and one all-volunteer hospice. The association between the two types of hospices is collaborative, while both types of agencies remain separate and autonomous, each providing the community with distinctly different services.

Through continued fundraising efforts, community awareness, and the growing needs of our county's residents, Hospice SLO continues to grow. In December 2001, Hospice SLO purchased and moved to its present home at 1304 Pacific Street in San Luis Obispo.

Currently, Hospice SLO has a professional staff including a full-time Executive Director, Director of Counseling, Volunteer Director and part-time Volunteer Director Assistant. We employ a full-time Event and Development Director. Three part-time Bereavement Counselors and 10 or more counselors meet with clients and facilitate support groups, while fulfilling their internships as bereavement counselors under the supervision of the Director of Counseling. The Hospice SLO office is run by part-time office assistants and several office volunteers. Hospice SLO currently has a roster of over 100 active volunteers.

Hospice SLO remains an independent non-profit organization providing volunteer and bereavement services not reimbursed by Medicare or private insurance.

II. ETHICAL ISSUES IN HOSPICE

A. Confidentiality

Confidentiality is an essential element in establishing trust between the hospice team, the client and his or her family. The gathering of sensitive and personal information is necessary in order to assess and understand the needs of the dying person and his or her family. All information about the client and family must be respected and shared only among hospice staff and volunteers as necessary.

It is when safety and trust are established that the hospice staff and volunteers are best able to work with the client and family in addressing their needs. Confidentiality and an unflinching respect for an individual's privacy are the building blocks for any trusting relationship.

References to the client/family by name are confined to contacts with those involved with care, either individually or at meetings. Information of extreme confidentiality divulged by a client or family member must not be shared in a group session unless it bears directly upon the care of the client. Such information may be shared with staff, however, if needed for the peace of mind of the volunteer.

At no time should a volunteer promise "not to tell anyone" any information alluded to by a client or family member. It is for the protection of both the client/family and the volunteer that the volunteer be allowed to use discretion as to whether information needs to be passed along to an appropriate individual, such as the volunteer coordinator or other care provider.

A signed oath of confidentiality is required of all volunteers.

B. Informed Consent

As an In-Home volunteer, it is helpful to be familiar with both the legal and ethical issues of death and dying, and working with the terminally ill. As a volunteer, you may be faced with legal and ethical dilemmas that will require the involvement of Hospice SLO staff, and clear communication with the families you serve is essential. Further information regarding your responsibilities as a volunteer and specific ethical guideline are covered later in this manual.

C. Client's Rights

The hospice program's concern for patient rights plays a significant role in guiding the program's services. "Client rights" refers to the process of empowering clients and supporting their self-determination.

The Dying Person's Bill of Rights was created at a workshop on *The Terminally Ill Patient and the Helping Person*, in Lansing, Michigan. It was originally published in the American Journal of Nursing in 1975. It reads as follows:

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness, however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention, even though "cure" goals must be changed to "comfort" goals.
- I have the right not to die alone.
- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and with dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to beliefs of others.

- I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face death.

Hospice SLO has also established a statement of client rights:

1. Hospice volunteer services are offered to provide compassionate care and support to the client and family and to help maintain the highest quality of life for the client.
2. Clients may expect that staff and volunteers have received extensive training in hospice care and philosophy.
3. The client will be treated with consideration, respect, and full recognition of individuality, including privacy in treatment and in care.
4. The client or responsible person will be fully informed of services available in the agency and of complaint procedures.
5. Hospice will keep adequate records and will treat with confidence all personal matters that relate to the client.
6. The client has the right to be served without regard to race, color, religion, national origin, age, gender, marital status, mental, emotional or physical disability, or sexual orientation.

D. Euthanasia

One of the ethical issues which arise from valuing a patient's right to direct his or her own care and treatment is assisted suicide, or euthanasia. The National Hospice Organization (NHO) passed a resolution which rejected the practice of euthanasia as inconsistent with the hospice philosophy of care.

The legalization of euthanasia is contrary to the most basic tenet of the hospice philosophy — that hospice care affirms life, and neither hastens or postpones death. A patient's request for euthanasia usually stems from fear — fear of pain and suffering, fear of being abandoned, and fear of becoming a burden to his or her loved ones. Hospice care proves every day that through skilled intensive pain and symptom management, combined with social, psychological, and spiritual care services, patients and families are able to enjoy a quality of life that is meaningful to them. Such care obviates the need for legalized euthanasia.

(News release dated March 29, 1993, John J. Mahoney,
President of NHO)

Following the November 1992 legislative initiative, California Proposition 161 (Death with Dignity Act), the Board of Directors of Hospice SLO voted to take a neutral stand on the issue of euthanasia.

The Hospice Patients Alliance affirms that all human life is inherently valuable and that the role of hospice nurses, physicians and all other staff is to alleviate suffering

and provide comfort for the sick and dying without sanctioning or assisting their suicide. A death with dignity allows for a natural death in its own time, while doing everything possible to assure relief from distressing symptoms.

III. THE HOSPICE EMPHASIS ON PALLIATIVE CARE, SPIRITUALITY AND GRIEF SUPPORT

A. Palliative Care

Aggressive treatment of a disease is questionable if it offers no real hope of curing or controlling the disease and if it can only bring further distress. It is at this point that palliative care becomes the most appropriate option.

Palliative care is the prevention of distress from chronic symptoms. It focuses on pain and symptom control, including special attention to the relief of physical symptoms such as coughing, nausea, constipation, vomiting and diarrhea.

Through a sophisticated use of polypharmacy (several drugs in combination), pain is anticipated and anxiety is reduced. The palliative approach to care also recognizes that physical pain is heightened by anxiety.

The idea of palliative care is to prevent pain from coming rather than trying to control it once it is present. Issues of drug tolerance and dependence are not likely when narcotics are properly used in treating the terminally ill patient. Furthermore, inadequate treatment of pain with an analgesic medication is likely to encourage craving and psychological dependence. The primary goal is to keep patients as pain-free as possible, yet still as alert as possible.

Alternative approaches that are non-pharmaceutical are available and supportive in palliative care. These alternative options include relaxation techniques, therapeutic music, massage therapy, Reiki, meditation techniques and more. Once again, hospice attempts to educate and respect our clients' and families' uniqueness in making choices that feel most appropriate for them. This may include one or all of the above choices.

B. Spiritual Care

Providing and defining spiritual care is a perplexing concept, because spiritual care and religious beliefs are somewhat different. In a broad sense, spiritual needs are universal in nature and address issues of nurturing and personal solace. On the other hand, religious needs focus on defined sets of doctrines, dogmas, and institutional and traditional observances and symbols. Although different, they do complement and affect one another.

Spiritual issues, including nurturing of the soul, the solace from spiritual tradition, and connection to humanity, need to be reviewed in light of each patient's tradition and beliefs.

As in all aspects of hospice care, the client's needs and beliefs will direct the course of spiritual care. One way to assess spiritual needs is to ask directly, "What nourishes your spirit?" The answer can range from reading the Bible to walking in a garden. For a patient

who can no longer read or walk in the garden, the spirit will be hurting. Only when we better understand the client's spiritual needs and values can spiritual care be provided.

People come to hospice with limited hope of recovery from physical diseases, yet they can redefine hope as the relief of suffering. Spiritual care is a fundamental part of providing this relief and finding meaning in the last days of life.

C. Grief Support

The terms “grief,” “mourning,” and “bereavement” are often used interchangeably, but there are differences in meaning. Grief refers to our reaction to loss, and encompasses all our emotional, behavioral, somatic and intrapsychic responses. Mourning is the cultural response to grief or "grief gone public," involving the overt expression of grief seen by others. In some ways it is helpful to think of grief and mourning as the two faces of loss — one that is seen outwardly and one that is carried inside and known only to the bereaved person. Hospice encourages the expression of grief and recognizes its social, religious and ethnic variables.

Bereavement, then, refers to the state of having suffered a loss; something has been taken away. It is the extended period of deprivation following the loss of a loved one. Hospice recognizes all the aspects of the death and dying experience and continues its support for the bereaved families and friends. Assessing the needs of the bereaved, both before and after death and developing programs and resources to meet these needs, is yet another essential component of hospice care. The medical hospice program provides bereavement services to survivors for a period of at least one year.

Bereavement services through Hospice SLO are not limited by the length of time since the loss. Services available include: support groups that deal with the issues of grief; individual and family counseling with trained professionals; a trusted and compassionate volunteer who will listen; education about the grief process; and coping skills provided in writing to assist with the stress of grief. These services are available at any time they are needed.

IV. THE ROLE OF CLIENT AND FAMILY

When serious illness or injury strikes an individual it can impact everyone to whom the effected person matters. Hospice care recognizes the responsibility of attending to the needs and experience of the patient with his or her family. In contemporary society, the meaning of “family” is not restricted to relatives by blood or marriage; operationally, family is understood to comprise a person's relatives and close friends.

According to the July 2012 article in Reuter's by Cynthia Ramnarace, “nearly three in four Americans over age 65 will require some form of long-term care during their lives, according to the National Clearinghouse for Long Term Care Information. And as many as 12 percent of nursing home residents are considered “low need” who could live in the community if they had the right support at home, according to the journal *Health Affairs*.”

The need for respite for caregivers will continue to increase as families do what they can to keep their loved ones at home as they face the end of life. The family members are seen as both primary caregivers and as persons in need of care. They must receive support for the

emotional and physical stressors involved in caregiving, so that they will continue to maintain their own health and well-being. The in-home respite care provided by Hospice SLO volunteers to individuals and families is a valuable resource and is a considerable contribution to the entire family's peace of mind.

V. SUMMARY

Hospice was introduced in the United States in the 1950s and continues to grow in availability and acceptance. The rapid growth of hospice care across this country is a testament to its necessity, both in terms of its fundamental principles and values and its practical support services.

Hospice SLO is a volunteer hospice and differs from the licensed Medicare hospice in that no medical care is provided and services are not reimbursed through Medicare, Medi-Cal or private insurance. Hospice SLO provides counseling, In-Home volunteer support and community education free of charge, receiving funding solely through donations and fundraisers.

